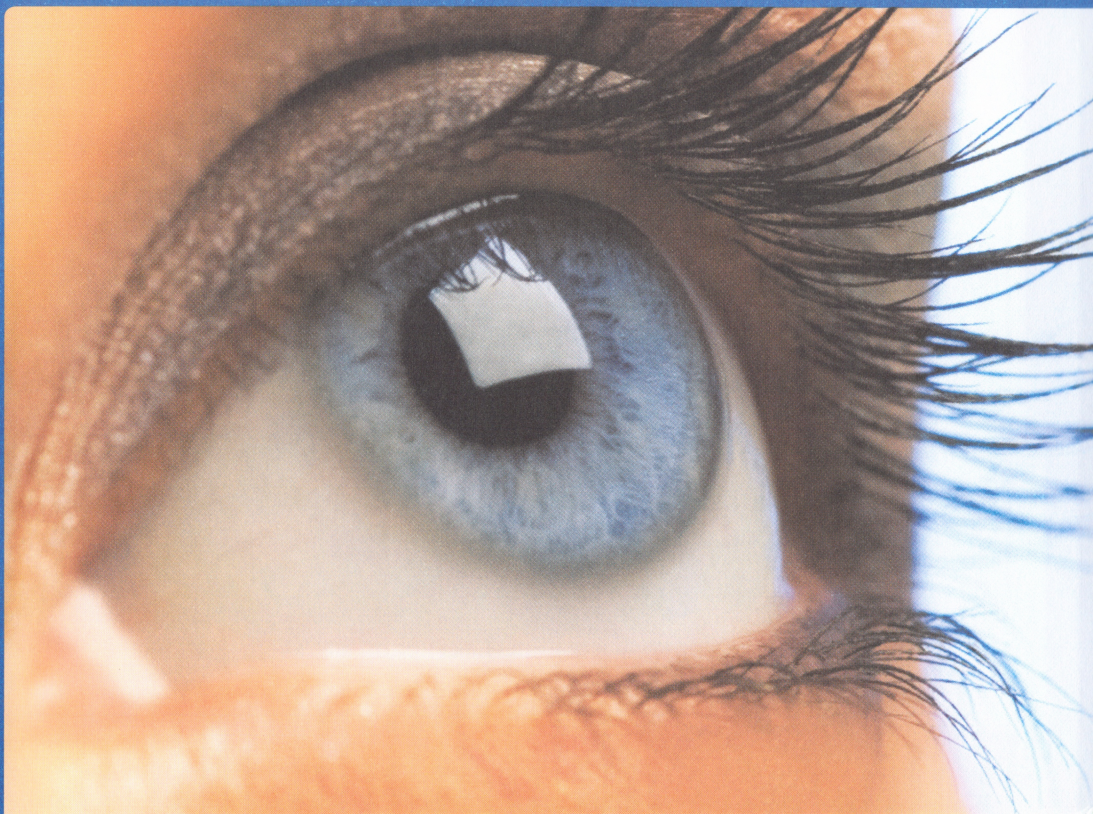
Macular Society

Beating Macular Disease

Your guide to

age-related macular degeneration



Macular Society

Beating Macular Disease

The Macular Society is beating macular disease every day. We have produced this guide to age-related macular degeneration to help explain the condition and how it affects people.

Being diagnosed with macular degeneration can be distressing, but with the right information and support, people can cope very well. There are now treatments for some types of the condition.

It's also important to remember that, no matter how advanced your macular degeneration is, you will not lose all your sight: macular degeneration is a condition that affects central vision only. Peripheral vision is not affected and macular degeneration is painless.

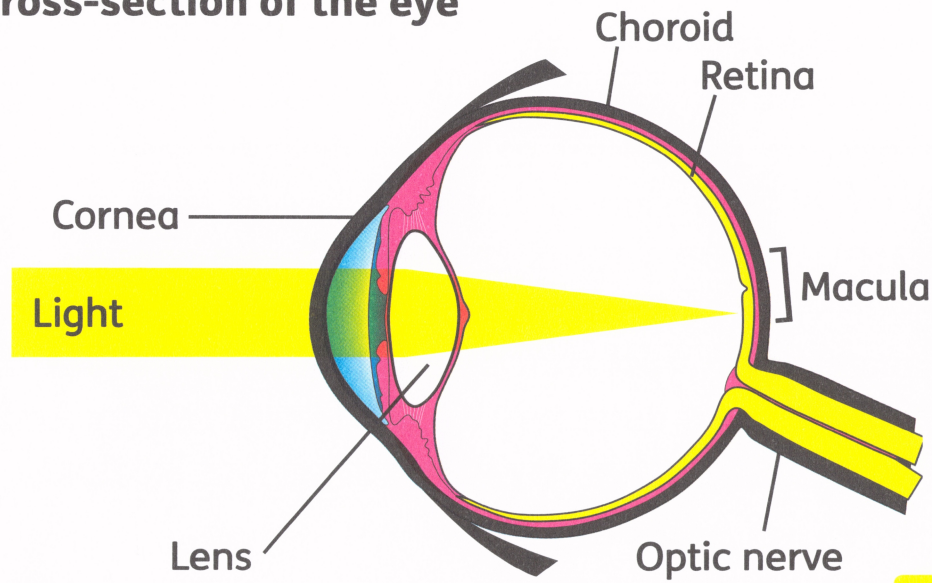
Advice and Information Service 0300 3030 111
help@macularsociety.org
macularsociety.org

What is the macula?

The macula is part of the retina at the back of the eye. It is only about 5mm across, but is responsible for our central vision, most of our colour vision and the fine detail of what we see.

The macula has a very high concentration of photoreceptor cells – the cells that detect light. They send signals to the brain, which interprets them as images. The rest of the retina processes our peripheral, or side vision.

Cross-section of the eye



What is age-related macular degeneration?

There are many forms of macular disease, including age-related macular degeneration (AMD). This usually affects people over 50 but can happen earlier. Macular disease is the biggest cause of sight loss in the UK, with AMD affecting around 600,000 people.

The older we are, the greater our risk of developing the condition. At 60, around one in 200 people have AMD. However, by the age of 90 it affects one person in five. We are, on average, living longer so the number of people affected is increasing.

There are two forms of AMD – **dry** and **wet**. Dry AMD is a gradual deterioration of the macula as the retinal cells die off and are not renewed. The term dry does not mean the person has dry eyes, just that the condition is not wet AMD. There is currently no treatment for dry AMD. The progression of dry AMD varies, but in most

people it develops over many months or years. Often people carry on as normal for some time.

Wet macular degeneration develops when abnormal blood vessels grow into the macula. These leak blood or fluid which leads to scarring of the macula and rapid loss of central vision. Wet AMD can develop very suddenly. There is treatment available for wet AMD.

Fast referral to a hospital specialist is essential.

Around 10 to 15 per cent of people with dry AMD develop wet AMD, so if you have been diagnosed with the dry form of the disease and notice a sudden change in your vision, contact your optometrist or hospital eye specialist urgently. If you have AMD in one eye, the other eye may be affected within a few years.

Other forms of macular disease include genetic conditions, which affect younger people. See our 'macular dystrophies' booklet for more information.

Symptoms

Macular degeneration affects people in different ways. Symptoms may develop slowly if you have dry AMD, especially if it's only in one eye. However, as the condition progresses, your ability to see clearly will change.

- Gaps or dark spots (like a smudge on glasses) may appear in your vision, especially first thing in the morning.
- Objects in front of you might change shape, size or colour, or seem to move or disappear.
- Colours can fade.
- You may find bright light glaring and uncomfortable or find it difficult to adapt when moving from dark to light environments.
- Words might disappear when you are reading.
- Straight lines, such as door frames and lampposts, may appear distorted or bent.

Normal vision

Vision with
macular degeneration

Late stage
macular degeneration

This distortion can be checked using an Amsler grid, (see page 20) or against everyday household grids such as bathroom tiles or a window frame.

Diagnosing AMD

The optometrist at your local optician's practice can test sight, prescribe glasses and check for eye disease. Some optometrists use photography or other imaging to detect early signs of macular degeneration. These might include Optical Coherence Tomography (OCT) scans which create cross-sectional images of the retina. You may be charged for these tests.

There is currently no treatment available for dry AMD so you might not be referred to hospital, unless confirmation of the diagnosis is required or the optometrist thinks you need a hospital low vision service. If your sight has worsened and you would like to be registered as sight impaired you

will need a hospital appointment.

In line with NICE AMD guidelines, if your optometrist suspects you have wet AMD, you should be referred to a retinal specialist at a hospital directly and seen within two weeks. If applicable you should be treated within two weeks after initial identification. You should not be sent to your GP. This causes unnecessary delay.

At hospital, further tests will confirm the diagnosis. The specialist may use:

- Eye drops to dilate the pupils to see clearly the back of the eye. These may make your vision blurred and sensitive to light for a short time so consider taking someone with you.
- OCT scans.
- Fluorescein dye angiography. A dye injected into a vein in the arm travels to the eye, highlighting the blood vessels in the retina so they can be photographed. The dye will temporarily change the colour of your urine, so be prepared.

Treating AMD

Wet AMD can be treated if caught early. Drugs are injected into the eye to stop the growth of the abnormal blood vessels. Following diagnosis, people will usually have a 'loading dose' of three injections, one a month for three months. A patient will then be assessed to see if more are required.

The injections are not as bad as they might sound. The patient's eye is anaesthetised and the needle goes into the corner of the eye so the patient does not see it.

A small number of people may respond better to a combination of injections and a form of laser treatment. There are a range of treatments and options, although not all are available on the NHS.

See our 'Treatment for age-related macular degeneration' leaflet for more information.

Causes of AMD

The cause of AMD is not known but there are a number of factors associated with the development of the condition.

Age

Age is the main risk factor. As we age, cell regeneration reduces. This increases the risk of developing the condition.

Genetics

A family history of macular degeneration will increase your chances of developing AMD.

Smoking

Smoking damages blood vessels and the structure of the eye. Smokers are up to four times more likely to develop macular degeneration than non-smokers. If you also have a particular common gene for AMD you are twenty times more likely to develop the condition if you smoke. Stopping smoking after you have developed AMD can also help reduce the risk of your eye condition getting worse.

Diet

A poor diet low in fruit and vegetables may increase the risk of AMD. Antioxidants and other substances in fruit and vegetables protect the body against the effects of 'free radicals'. These are unstable molecules that damage cells or prevent cell repair.

Alcohol destroys antioxidants. Obesity and a diet with lots of sugars and hydrogenated or saturated fats also increases the risk of developing AMD.

Blood pressure

People with high blood pressure are one and a half times more likely to have AMD than those with normal blood pressure.

Gender

AMD affects men and women equally. Women typically live longer than men, so more women are diagnosed with AMD.

Protecting your eyes

You cannot change your age or family history but lifestyle changes may help protect your eyes.

- **Do not smoke**. This is the most important self-help measure you can take. If you would like help to stop smoking speak to your GP.
- Maintain a healthy weight and blood pressure.
- Wear a hat with a brim, visor or sunglasses to shade eyes from direct sunlight. Macular cells are sensitive to both ultraviolet (UV) and blue light.
- Have regular eye tests to spot problems.
- Monitor your vision to check for changes.
- Don't drink alcohol to excess.
- Take regular exercise.

Nutrition

A good diet is important for eye health because certain nutrients protect the body from damaging substances called oxidants. In the eye, oxidants may contribute to the development of AMD because they speed up cell degeneration.

Antioxidants like vitamins C and E, and a group of substances called carotenoids reduce this damaging effect. Two important carotenoids for people with AMD are lutein and zeaxanthin, which are found in dark green leafy vegetables like spinach and kale.

Eating a Mediterranean diet rich in green vegetables, fish and white meat can reduce the risk of your AMD progressing. Some experts recommend eating at least 10mg of lutein a day.

Eggs also contain lutein and zeaxanthin, and zeaxanthin is found in orange and yellow fruits and vegetables such as sweetcorn and orange bell peppers.

Nutritional supplements

Two large studies in the USA, the Age-Related Eye Disease Study (AREDS) 1 and 2, have found that certain nutritional supplements may slow down the progression of AMD in people already showing signs of the condition.

AREDS supplements are available in the UK but they are not suitable for everyone. Your ophthalmologist or GP can advise you. For further information, see our 'Nutrition and eye health' leaflet.

Please talk to your GP before taking supplements or making major changes to your diet, especially if you take other medications.

Living with AMD

Macular degeneration is a very frustrating condition which can greatly affect your day-to-day life. However, there is plenty of support and information available. Even if your sight is still good and you are having treatment, it's important to know how to look after your vision and what to do if your AMD reaches a stage where you struggle with daily tasks.

Here are some ideas to help you manage AMD.

- Improve the lighting in your home and workplace. A person with normal sight needs twice as much light at 65 as they did when they were 21. A person with AMD will need even more. Control glare and keep general lighting levels bright and even.
- Use adjustable, cool to the touch task lighting for reading and close-up tasks.
- Bright and contrasting colours can help differentiate between objects.

- A wide variety of low vision equipment is available, including magnifiers. You may be able to buy or borrow them from your local low vision service.
- Try spectacles with filters that block UV and blue light. They help protect the eye and reduce glare.
- Computers have options that can read text and emails as speech. E-readers, such as the Kindle or iPad, mean you can read books in large format.
- Buy or borrow large print books, audio books, newspapers and magazines.
- Use talking equipment such as watches, wall clocks, microwaves and kitchen scales. Audible liquid level indicators warn when a cup or jug is full.
- Tactile bumps help you find settings on appliances such as washing machines.
- Use large face clocks and watches, large print stickers for keyboards and telephones with large numbers.

It's hard to know what equipment to buy but there are plenty of organisations to advise and help. These include low vision clinics, social service sensory impairment teams and local societies for visually impaired people.

Charles Bonnet syndrome

Up to half of all people with macular degeneration are thought to experience visual hallucinations at some time. The condition is called Charles Bonnet syndrome. These images might be of people, animals, landscapes or patterns.

People who haven't heard of it often worry they are developing a mental illness, but it is a normal response of the brain to sight loss.

As fewer messages reach the brain, the cells that normally process vision can

An example of a visual hallucination

become hyperactive and create images of things that are not there.

Not everyone with vision loss has hallucinations. They may occur once or twice, or continue for several years or longer. If you would like to speak to someone about hallucinations call 0300 3030 111 or visit **macularsociety.org/visual-hallucinations**

There is further information on living with macular degeneration in several Macular Society leaflets:

- Diabetic macular oedema
- Nutrition and eye health
- Protecting your eyes
- Smoking and sight loss
- Visual hallucinations.

Call our Advice and Information Service 0300 3030 111 or visit **macularsociety.org/resources**

Amsler grid

Use an Amsler grid to monitor your vision in case it changes. It is important to spot early signs of dry AMD becoming wet, or wet AMD becoming more active.

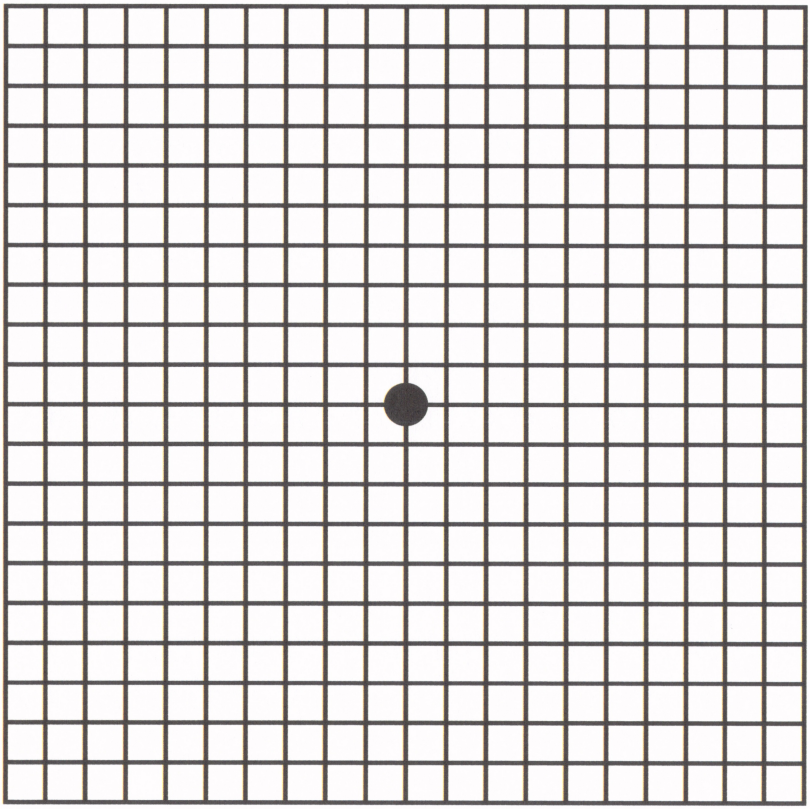
Wear any reading glasses you normally use (but not varifocals).

Hold the grid about 12 inches (30 cm) from you, where it is best in focus.

Cover each eye in turn and look at the central dot.

If you have AMD, the lines of the grid may appear wavy or broken. Parts of the grid may be blurred or missing.

If you see **any changes** to your vision, contact your ophthalmologist immediately. Do this check as often as your optometrist or ophthalmologist recommends.



Beating macular disease

Macular disease is the biggest cause of sight loss in the UK, with around 300 people diagnosed every day.

The Macular Society is the only charity determined to beat the fear and isolation of macular disease with world-class research, and the best advice and support.

To support people affected by macular disease now, the Macular Society provides a range of support, information and services. These include:

- The **Advice and Information Service (0300 3030 111).** Available Monday to Friday, 9am to 5pm. Alternatively, you can email help@macularsociety.org

- Our website at **macularsociety.org**, which provides a wide range of information and resources for people affected by macular disease.

- Our network of over 400 **Macular Support Groups** across the UK. Each one offers practical and emotional support for people with macular disease, from those living with it today.
- Our free, confidential **Counselling Service**, which offers support over the phone from one of our trained counsellors. You can also call our Advice and Information Service for more information and to be referred for counselling.
- Our **Telephone Befriending Service**, which pairs you up for regular telephone calls with another person with macular disease who knows what it is like to live with the condition. Calls can be about anything, and provide friendly support.
- Our **Treatment Buddies Service** will connect you with someone else who has received treatment for macular disease to talk you through the process and any worries you may have.
- **Skills for seeing training**, which can help you learn techniques to make the most of your remaining vision.

Can we support you?

If you are living with macular disease or have recently been diagnosed, we are here to help. We can support you, whatever stage you are at. Try our **six months free membership**, which includes:

- Sideview, a quarterly magazine packed with news, research updates, inspirational stories, tips and advice.
- Our monthly e-newsletter.

To join, go to **macularsociety.org/sixmonthsfree** or call **01264 350 551**.

Macular Society

PO Box 1870, Andover SP10 9AD

01264 350 551
macularsociety.org
info@macularsociety.org

@MacularSociety

/macularsociety

Macular Society is the trading name of the Macular Disease Society. A charity registered in England and Wales 1001198, Scotland SC042015 and Isle of Man 1123. A company limited by guarantee, registered in England No. 2177039. Registered office: Macular Society,Crown Chambers, South Street, Andover SP10 2BN.

Trusted Information Creator

Patient Information Forum

FSC
www.fsc.org
MIX
Paper | Supporting responsible forestry
FSC® C095194

MS002 | 0322 | 0323